



Presidential Commission
for the Study of Bioethical Issues

TRANSCRIPT

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DR. GUTMANN: So I'd like to start off with a question for each of our terrific speakers to answer. It's purposely requiring you to be selective and pick one important initiative or step that the Bioethics Commission can recommend for effectively integrating ethics into the practice of neuroscience. This is a recommendation we're almost certainly to make.

There is as you heard earlier today a consensus on our group that it's important to integrate ethics early on rather than have it outside as the policeman or woman to hand out the punishments, because we really have consistently said that good ethics and good science go together. So I would like to just go down here and ask you for one specific way, or if you disagree with that, tell us one reason you disagree with it, but presuming right now that you agree, one specific recommendation or part of a recommendation that would help in that regard.

And just so you know what I want to get through, we also have three questions that I'd like to pose anyone who would like to answer them on the Commission, or the presenters from august members of our audience. But let's start with, okay, if you're in favor of integrating ethics early on into neuroscience, how do you do it? Peggy, would you like to begin? One thing.

DR. MASON: Not really, but I'll go for continuing education for senior scientists.

DR. GUTMANN: Okay.

DR. NEILL: I think that if you have the power to require people submitting to journals, or that there be any funding of journals via publication charges, et cetera, that the journals also are required to do screening practices is some of those that I have outlined here.

DR. GUTMANN: That's terrific and we hadn't heard that before. And you sit in a position that you actually practice that and I think given that the incentives are to publish, that could have a significant effect, so thank you for that. And we've also heard about how important continuing education is. Yes.

DR. WARD: Incorporate a media literacy and media criticism program within the discipline with very strong links to schools of journalism and communication.

DR. GUTMANN: Okay. Timothy?

PROF. CAULFIELD: I'm going to cheat because I'm going to call my recommendation the creation of communication standards that would involve many of the things I talked about and some of the things other people have talked about, but really along the entire pipeline of communication. So get recommendations, ethical recommendations on how to begin.

DR. GUTMANN: Thank you. Eric.

DR. RACINE: Well, it's hard to choose but an interesting I think bet would be on the younger generation and exposing trainees in neuroscience programs for example to ethics as a creative scholarly slash practical enterprise I think would be my -- where I would bet my money I think.

DR. GUTMANN: Yeah.

DR. STENECK: I was actually going to agree -- I would focus on new students and new faculty with continuing education.

DR. GUTMANN: Great. So one of the things that ties the younger and educating younger, which I like, Eric, what you said and we've heard it earlier, is making ethics education challenging. The problem with late-end training courses -- and not that you don't need them. Yes, you need people to follow the rules, but the problem with them in a setting where people are highly educated, used to dealing with intellectual challenges, is there's nothing intellectually challenging about them, whereas understanding what the highest demands and duties and desiderata of ethics are is a very challenging thing and to teach it in a challenging way early enough on that people who become scientists have time for it and to appreciate the intellectual challenge of it is really, really important.

Because as you can see, everything, all the issues we get to deliberate about are not simple issues. I mean, we do the simple ones but -- quickly -- but the difficult ones are ones you want scientists to appreciate and to really appreciate the intellectual challenges.

So those comments are well taken. I open it -- I open it up and I will interrupt at some point to ask these other questions. Raju.

DR. KUCHERLAPATI: I just wanted to make a comment and a question. So one of the comments, Amy, is that certainly at all institutions, and your institution, and I think all of the major academic institutions, all of the graduate students and medical students do take an ethics course on responsible conduct of research. And the NIH, which provides training grants, actually mandates such training.

And so there is extensive training and obviously every institution that provides such training they use different types of methods to do so, whether it's didactic, or interactive, or case studies, or whatever the case may be, and that is extended not to just students but also to fellows and post-graduate members of the community, and the faculty are required to have -- to take an online course on certain aspects of conduct of research and so on.

So the question is that do we feel that the existing systems for training people, are they inadequate, do we need to augment them in some way, and if so what to

do -- what do you think are the ways that we could augment the current programs?

DR. GUTMANN: Peggy.

DR. MASON: As it turns out I sit on the GMS training grant study section and so I review everyone's RCR plan. And when we do site visits, which GMS still does, we get to talk to the students about their experience in RCR, and I can tell you that it's extremely varied.

What we want is engaged students that get that these are questions for which there are no clear answers most of the time. What we get I would say probably 50 to 60 percent of the time is very disengaged, I got to check off this box.

And so I don't know how to do it but somehow we've got to make ethics less -- and I remember something that you said, Nelson, about setting standards, and I think that if we approach it from a setting standards point of view I don't think it's going to be -- I don't think it's going to capture their imagination. If we set about it from a questioning point of view, from an intellectual inquiry point of view, then I think we've got a shot at it, we got a shot at making them engaged and interested, and see, that there's complexities. I can tell you that in the almost year that we've been live as an ethics committee I'm amazed at how many new ways in which these cases can challenge my abilities to even evaluate them. I mean, there are just endless intricacies. So I want to get away from the cut and dry and towards the excitement of ethics.

DR. GUTMANN: So here's one answer from both evidence and experience. Just as you wouldn't want students to be taught genetics by somebody who was not an expert in the science of genetics, so you shouldn't want scientists to be taught ethics from somebody who is not expertly trained in ethics. It's really not exciting or very edifying to be taught ethics or bioethics from somebody who basically thinks I've got to get my students through this and here are the 5 things you have to know, or 10 or 20.

No, no. It's not the way it is at your institution or mine. My institution has a bioethics class that's now tuned into -- but it is that way in a lot of -- and it's -- I'm sure there are pockets of our institutions where it is that way, where senior scientists do that, and a lot of senior scientists weren't required when they went through the ropes and they see it.

So it's not all rosy out there, Raju. There are a lot of -- I've come across, just as I've come across a lot of people in ethics who don't have a clue about science, I've come across a lot of people in science who don't have a clue about ethics. And our job is to integrate them, and that's true I think in my experience even at the best institutions, and if it's true at the best funded institutions it must be true at other institutions as well.

DR. KUCHERLAPATI: If I may comment. As we pointed out earlier

resources are always an issue if we want to be able to recruit a hundred new ethicists to be able to come in and train our students and fellows, and I think it may be impractical. So, I mean, I don't know what other institutions -- at least at our institution for example, every year like 20 different faculty members that are actually involved in this ethics education, these are volunteers, they want to come in and teach ethics and be able to participate in ethics. I think it's actually fantastic. They're not trained in ethics, but they are seriously interested in the issues.

And I think as Peggy pointed out it is not so much the solutions, it is a way of thinking about the problems, and at least I think in this model can also work. I think that having card-carrying ethicists certainly would be great, but in the absence of that, having a broad spectrum of faculty involved in it may be equally good.

DR. GUTMANN: If you have a broad spectrum of faculty, none of whom have had serious training in moral philosophy and ethics, I think you're falling short. And just as if you had a broad spectrum of faculty discussing science, none of whom had a basic education in science, I don't think that's what we do, Raju. So I'm not -- you know, that was what -- but I think we do have in every major medical school that I know of and every major institution has wonderful faculty members who are trained in ethics and working with faculty members in science.

But I think you need that. I don't know how else you can do it. It's a discipline like any other discipline.

Ushma.

DR. NEILL: Just really quickly. I've been part of the RCR education at Memorial Sloan Kettering at Cornell and Rockefeller. Journal editors love to talk, they love to meet people. So we're sort of at the interface between scientists and people going through this and being able to show practical examples. So if you need ambassadors, we're very cheap ambassadors.

DR. GUTMANN: Paying ad. Very good. Stephen.

DR. WARD: Thank you. Just to enhance on remarks made, we have the same problem in teaching journalism and ethics, media ethics today, only given the problems I've just earlier noted it's even more complicated. What's actually -- what you need is convergence of theory and practice in a very dynamic way, and that sounds like it's easy to do. No, it isn't.

What you have to -- what I do is, I'll talk personally, is I start from where the students are. It's always good teaching methodology, but I don't stay there. I start with the issues they're dealing with, the problems they're about to confront. I start from the experience of tension and doubt that is -- that makes it an ethical problem in the very first reason. But I quickly get them to bring frameworks, theoretical perspectives upon us, and they see the relevance of theory because theory bubbles up from the experience

itself and then it makes sense.

And then they have to do specific projects. For example I picked some very contentious areas of journalism, for example how should journalists use, professional journalists who work for corporate, for media, use the internet. Their editors say brand yourself, get on there, say personal comments but we'll fire you if you step over the line and we have no idea where that line is. And people have been fired.

So, you know, I take areas like that and I try to get them to write their own particular guidelines or frameworks around that. I'm a big believer in philosophy, which I am. I'm not -- I went into journalism after philosophy. I'm still a philosopher primarily. But you cannot avoid bringing to it the substantive insights of philosophy, but you've got to do it in a way that they don't yawn. And I got to tell you if you teach it properly I think you can do it.

The other thing I would say is can we -- what I would hope is that something like journalism ethics would stop being siloed in schools of journalism as one course or whatever, but team-taught across -- for example we teach strat comm at our place. So why aren't we having team-taught courses where we show the students that the ethical issues actually are shared among various disciplines?

And then let's tie that -- and this will be my last sort of thing I'll say on this -- I think I mentioned it before, I'm hyping this one, is that then we link that, those ethics courses to a cross curriculum approach where young students who are using media themselves get to understand the impact, the ethical consequences of that new media themselves and they get to talk to professionals who are also dealing with similar problems.

I'll stop there. But those are some ideas.

DR. GUTMANN: Thank you. Thank you. Jim.

DR. WAGNER: I've forgotten which of you three had said something about the -- that communications is now part of good science, it needs to become a part of -- was that you Timothy? So thank you for saying that.

We've been talking about communication from scientists and from scientists we understand that there are certainly potential temptations for inaccuracy and hype, and those temptations are they need to be published and they need to be funded -- and they needed to funded. For the journalist the temptations that get in the way of good communication is that they want their work to be read and they want their media to be sold.

One group we haven't talked about much is the public, and inasmuch as we have as a Commission often talked about education goals I wonder about some of those education goals. I now will borrow from a conversation that many of our faculty

are having at Emory, and by the way encouraged by a very quick conversation with Jonathan Moreno's class at Penn. This is a conversation about teaching something broadly about the nature of evidence, the distinction between primary evidence and derived evidence and the integrity of information, something that can be taught not just to -- not just to folks doing neuroscience or any particular science but is presumably of value to historians and to lawyers and to just about everyone else.

Talk to me a little bit about what we might recommend with regard to educating the public about the nature of evidence. Timothy.

PROF. CAULFIELD: Well, I had my hand up and it was like you read my mind because this was the comment I was going to make. I don't think that -- I mean, I love the idea of emphasizing ethics, but so many of the issues associated with the challenges we've talked about today I don't know if they're going to be solved by ethics because there's, as I said, there are system problems about -- which touch on incentives.

But I completely agree with you. I think that we need to teach our public, I'm talking from elementary school forward, about critical thinking. Now in -- my kids got taught. I don't know if this happens in the United States. They actually had a class on critiquing media and talking -- and also about the very basic science things that you just mentioned: was this an animal study, how big was the "n," is it an association study. All of those things are very, very -- I think are easy tools that can be communicated to the general public.

So I completely agree with you and I also think -- I don't think we can downplay the importance of trying to change some of the incentives that are creating the hype, because changing behavior is incredibly difficult. No matter how much you educate people about ethics a lot of these things are still going to happen, right. We need to at least think about changing some of the incentive structures around publication, funding, translation pressure and career pressure. Thanks.

DR. GUTMANN: Thank you, very helpful. Dan.

DR. SULMASY: First a comment back to the discussion between you and Raju. Again I'll be the person here saying we shouldn't consider this to be an either/or situation, just as I made a similar comment in the first panel.

I think that -- I'm in 100 percent agreement that we need to have people who know the science of ethics and can talk to people about it. I mean, there's a basic science to ethics and its philosophy or, you knew, theology. We need people who are able to do that.

Nonetheless we can in fact do for scientists, and I don't think it's done as much for scientists as it is for clinical ethics, do faculty development programs for faculty who are interested scientists to give them some more tools than they have now and have them be small group instructors for a course in which there is some kind of

teacher who has the expertise so that you don't have to have these two separate from each other.

And again that model works in clinical ethics. I don't think it's used so much in scientific education, I think would be scientific ethics, it would be useful.

Second, once we do that then there's the question of what to teach, and I have to say that from the last panel I was, you know, a little disheartened to hear for instance Dr. Neill very much saying there are standards, there is truth, there is objectivity, and then immediately following her to have Professor Ward saying that the movement within journalistic ethics is, well there is no view from nowhere, there is, you know, no capital T truth, and there are only at best procedures. Right, you might, but if that's where the trend is going then the question is what do we teach?

I mean, is there only a procedural ethics for science as well as for journalism or should we, you know, have our small groups in which case students say, well, I feel this way and you feel that way and then we leave it at the end of the day. They might be interested but not have any content. Or should we say that, you know, at least there are some things we ought to be teaching. There might be some gray areas but there's some things that are clearly beyond the pale and we ought to set standards for them.

DR. WARD: You mentioned me. Yes, we need procedure and content and the content is the controversial side because of sort of a rampant of relativism, assumptions out there. But I don't think journalism ethics stands on its own feet. Ultimately it stands on certain social and political goals.

In this country most ethics is based on a type of democracy. Why would you believe in watchdog journalism if you didn't believe in democratic citizenship and the power of informing citizens? There are political and social goods assumed.

Now there might be other countries where they're not assumed, but at least you could start from that -- they are very broad. They're getting even broader by the way, because now we're in an era of global journalism. We have to redefine some of those content goals in terms of global -- the global good as it were, so when we cover something like climate change, international agreements, or global poverty, or whatever we have to sort of shift from nationalistic, patriotic schemes to a much broader cosmopolitan ones.

Now I don't want to get much into this. All I'm saying is you cannot escape some sort of content assumptions, and I don't think there's anything wrong with that as long as you can argue for them in a plausible manner.

DR. GUTMANN: I took Dr. Ward to be, or Mr. Ward to be saying that the state of journalism today all in -- if you consider everybody who practices in the communication field a professional journalist they can't agree on any substantive

standards. And that's a problem because process alone is not going to get you any sufficiently defensible set of ethical standards for journalism or any other profession.

DR. WARD: If I just may. There is movement right now towards what I call recreating media ethics around certain norms that may be able to attract a greater coalition of agreement than the old model. A lot of people think it has to drift from the area of transparency rather than objectivity. I disagree, but anyway -- and to move towards a form of journalism that is much open to different types of journalism, not just objective reporting but see some value in advocacy journalism that before would have been shunned as un-objective.

I'm not -- sorry about gloomy Gus on this -- I actually think it is a tremendous opportunity to redefine what journalism is and that's what I'm interested in doing.

DR. GUTMANN: Let me go to some of the questions and then come back to this. Faith Lagay, do I have -- is Faith here? Yes, Faith from the AMA. She's the director of the Ethics Resource Center at the AMA.

The Commission seems to have considered the ELSI model where a specified percentage of research funding is mandated for ethics research. This is not to say that an ethicist has to be part of the team, but that the ethical implications of the research must be looked into. Have you rejected the model and if so why?

So the answer is, no, we haven't rejected the model. Neither have we decided to recommend that model. We've heard both sides of it, we've heard people who have recommended that we recommend some kind of ELSI model. We've heard other people who say that that actually led to a silo effect that is less desirable than if you could figure out a model that integrated ethics early on.

And so we're looking for a model that takes ethics, the ethical, legal and social implications of neuroscience even more seriously than the ELSI model by integrating those considerations early on in the life of neuroscience, and in fact basically follows what Dan Sulmasy's response to the interchange between Raju and myself, which is to say, look, we can and we should do both. With limited resources we should make sure that people who are trained in ethics early on get into the conversation about neuroscience and neuroscientists themselves take on the responsibility of integrating it into their enterprise.

Because if you always have this separation that's not -- that's not healthy. I think that's basically where we are now, but we're not yet ready to make specific recommendations. Yes.

DR. KUCHERLAPATI: I think that, you know, we probably need to have many different models to accomplish the goals that we need to accomplish. I'll give you a specific example. I think like, you know, the last report from the Commission on

incidental findings, this is a recommendation that this Commission considered and sent out recommendations. And that's a problem that is dealt with by a lot of different people, whether academic people, or imaging people, or consumers and so on and so forth that are applicable.

So there is a body like ours that can deliberate on that and make recommendations at the highest level then hopefully that will, you know, go down. That's one type of model.

Another type of model is that if at any of our institutions there are a group of five or six investigators wanting to think about a new research program they need to consult with somebody there about that particular program, right. So these are completely different models and we need to have space, you know, to have opportunities for both kinds of models.

There are some big problems that the ELSI kind of model would be able to solve and other types of problems which only a different kind of model, the distributive model can solve. So I think that maybe we have the opportunity to be able to do something more than what ELSI was able to do.

DR. GUTMANN: Nita.

DR. FARAHANY: First let me thank everyone. It has been such an enriching conversation today. And it's been something that all of us have been thinking about quite a lot.

I've been thinking about at Duke we're launching an initiative in science and society, one component of which is about science communication. And one of the conversations that we've had over and over again and that I heard echoed on this panel is how you create a culture of change and the mentality of what science communication is. And there's one side of it of course, which is journalism and the coverage of scientific information, and then there's the other aspect of it, which is engaging scientists and responsible science communication.

And something -- you know, some of the things especially that you said, Tim, about the issues about incentives for scientists and engaging in communication I think is really tough as a problem to solve because scientists are either incentivized to communicate in order to over-hype the significance of their research, in order to get grants, or they're discouraged from being part of the public conversation because it's not viewed as hard core science and it's not viewed as respectable to be out there in the public eye, or they're dumbing down their research in order to be communicating with the lay public, or they're terrified of communicating to congressional leaders or to legal audiences because of the distortion of the science.

And so that, you know, that -- these different incentives that are pulling them away from communicating science to the lay audience, to legal audiences, to

congressional audiences, to legislative bodies, seems to me to be such a problem that has to be overcome, and what I would love to hear your ideas and thoughts on is to how we create a cultural shift so that it is a conversation also about ethical and responsible science to be part of the conversation, to be accountable of the science. Simply saying it isn't enough. How do we change the incentives to make it possible?

DR. GUTMANN: Eric.

DR. RACINE: Just a very concrete example coming from your Canadian neighbors.

DR. GUTMANN: Notice how they remind us.

DR. RACINE: We're just trying to put things into context to make sure that –

DR. GUTMANN: Sure.

DR. RACINE: -- I'm not saying anything wrong here. But basically we've had a program, I'm not sure even now that it's still a program, it's taken a life of its own, of what we call Café Scientifique, or scientific kind of coffee shop conversations which are meant to actually foster interactions between scientists, scholars and the general public.

And initially I think this came a bit more by the top down I would say from CHR or NIH, but now it's taken a life of its own and I think it's becoming valued within our academic context, where when you haven't done such a thing it becomes like a bit of a strange aspect of your own academic life that you haven't participated to such a public conversation.

Now this is a very local type of initiative. You'll reach 70, 100 persons per event. But if you multiply those events and you create a culture then, you know, you could have some more general effect. And I think now institutions are buying in, and tomorrow night I actually have one at my institution dealing with, you know, conversations about free will and neuroscience.

And my own institution has provided a lot of support, making it very easy for me and my colleagues to be engaged. It's very lightweight.

DR. GUTMANN: And if we're serious as we are talking about academic institutions of wanting to encourage our representatives to fund science research we had better, as you and Nita suggest, encourage our scientists to communicate out to the public.

So we have something called the Science Café in University City, West Philadelphia. We get members of the public who love the idea of coming and hearing one of our scientists talk about her, his discoveries, and it does multiply. You can't do

this -- I mean, journalism does this at the big scale. We do it now with what are called MOOCs, massively, open, online courses which we have in bioethics and in science and medicine.

But that's not a substitute for what you were talking about, which is really getting out in the community and doing face-to-face interaction, really important.

I have Peggy. Eric you wanted to follow up quickly and then Peggy. Go ahead. Did you want to quickly --

DR. RACINE: Maybe one good aspect about such a program is there's actually like limited costs. This is something that is approachable and doable and doesn't require extensive funding.

DR. GUTMANN: Yes. Although we also have, and I know Nita is aware of this, we have professionals -- this is where professional journalists are extremely helpful. We have professionals who help our faculty translate, because let's face it, we're not recruiting faculty who are expert in translating what they do into ordinary language. I mean, science journals are not readable by an average college graduate, right. So we do -- it takes some investment, but it's well worth it.

I think if we -- if we stop caring about the public understanding the importance of research we're giving up, especially in this country more so than in Canada where there's more of a tradition of understanding it, you may not think as much as you want but much more so than in this country. Really important. Peggy.

DR. MASON: I just wanted to address what you said. I am a big believer in MOOCs. I think that that is a fantastic way to interact with the public. I think that you, Anita, that you're absolutely right, that there's this ridiculous attitude of looking down at people that want to communicate. You know, it's the Carl Sagan attitude enlarged.

DR. GUTMANN: You mean the critique of Carl Sagan?

DR. MASON: Yes, people looking down on his science because he deigned to communicate with the public. And to be brutally honest I -- one of my failings -- I think it's one of the great things about tenure. So, you know, once you get there it doesn't really matter what -- if other people are looking down on you for doing it. And to me one way or another we all basically work for the taxpayer, so we owe them and MOOCs is one way to pay them back.

DR. GUTMANN: Thank you. Anita. Not to be confused with Nita.

DR. ALLEN: My question kind of goes to Mr. Ward. Very interesting discussion we've been having about how we can reach the public, and we just heard that one way to do it is for scientists to speak directly to the public. We also heard the

suggestion that maybe in-house communication professionals could translate the science from the scientists to the public. And you were talking about, you know, newspaper journalists and implicitly about bloggers and op-eders and tweeters and YouTube, with all the decentralized now quasi-journalists.

One type of person you didn't talk about explicitly was the science writer and I'm wondering where you see the science writers fitting in. If I'm imagining that schools of journalism would have programs that are focusing on science writing and the person who, you know, obviously comes to mind in this connection would be Matt Ridley who has written three or four books about genetics. And he's a very popular writer. I've written a paper criticizing some of the ways in which he attempts to communicate genetics information to the public.

But I'm just wondering is this something that we should be doing in schools of journalism that's actually cultivating, creating specialists who are adept at science writing, including the ethics of science writing?

DR. WARD: Yes, it's very important. And the Council of Science Writers in Canada, I've been involved with them a lot. So, yes, science writers play an incredible part. I would call -- there is at the academic level --

At UBC, I started the science journalism program there, one of the first in Canada, and I started it because I thought we needed in addition to general reporters we needed knowledge professionals, journalists who actually knew something about the work they were writing about, so they were not --

What we haven't talked about is our journalists are intimidated at press conferences because they don't know enough about science to even ask the right questions.

Or by the way, news routines, what we think is a story totally affects what we cover. But those are other factors.

In terms of science writing, the program we set up, and I'm not setting it up as a perfect model, was that the Master's students had to make a particular part of science or the environment or whatever -- some very serious part of their studies -- as part of their expertise, and hopefully, they would go on to take that knowledge to the polling.

I think there are other ways that we have to do it than rely on that. What would happen if we in fact started to establish centers for journalism, science journalism -- whatever you want to call it -- of excellence. Projects within schools of journalism.

Led perhaps by fellows of science, acting as fellow, chairs, of the environment, say, in Portland that's come to terms and one gives me a chair in environmental studies. That is happening in other areas of journalism which is

non-profit journalism right now, across many academics, now the location for centers for investigative journalism.

Because there wasn't sufficient support in mainstream media, in newspapers, a lot of those people de-camped to universities and set up websites where online they do investigative journalism sponsored by foundations and whatever.

And I think those are perfect places where you could have that sort of nonprofit science journalism. It might be interesting if you give it a try. But, you know -
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DR. GUTMANN: Thank you. Let me take another question from Yvonne Lans, who is at NIH.

DR. LANS: Basic scientists often refer to poorly done science such as poor standards of recordkeeping as just sloppiness or scientific sloppiness, and having nothing to do with scientific integrity.

What does the panel think about the notion that adhering to scientific principles and keeping accurate research records, et cetera, as a fundamental duty for all basic scientists, just as scientists in clinical research have to adhere to certain duties, such as beneficence, hence promoting duties for basic scientists are a set of core values, these become really important. The idea of doing good science, not being sloppy is a duty, an ethical duty. Ushma.

DR. NEILL: While I was at JCI, I cannot tell you the number of different excuses that I got when people were unable to come up with replicates, the original data.

There was one, one I referred to, a lost USB drive, it was in my suitcase in the back and then I got in an accident and the police have confiscated my suitcase, and that USB drive was the only place where I had my data. We did not buy it. That's really kind of ridiculous.

Was there any listing in your lab notebooks that the experiments were done, send us pictures of your lab notebooks, all of these things.

After that, I started having informal conversations with scientists at various conferences, how involved are you in looking at your students' lab notebooks, have you ever gone through them, or when they're presenting their data at your weekly meetings, are you going through these things and every one of the replicates, are you making sure that everything is in there.

And I would say a good 90 percent of them had never looked at their students' notebooks. And I berated a lot of them saying you have no understanding of just how important keeping track and being accurate and being deliberate is.

These are the things that are drilled into us as students, that when you're a scientist, you're supposed to be specific, you're supposed to be logical, and then they just completely lose sight of it.

And I understand you need to trust the people that you are working with, and it is all based on a foundation of integrity. However, it was shocking to me when I actually did sort of an informal poll of how little people were doing that.

So, I think Yvonne's question gets at something that is rather pervasive that should be drilled into the training of senior faculty and not just junior faculty, that they need to be more deliberate about going over these things.

DR. GUTMANN: Yvonne, the answer is a resounding yes, it ought to be clear that good -- again, that good science and basic ethics of good science, very important.

Nick?

DR. STENECK: The framework for U.S. policy was set in the late 1970s when misconduct first became an issue. And at that point, the research community was very worried about being over regulated, and that is when the terms fabrication, falsification, and plagiarism were invented.

There actually was a clause which existed for many years which said -- and other practices seriously deviate -- and the scientific community lobbied and eventually got that clause dropped out of the 2000 definition.

Other countries are taking a totally different approach to integrity in research. The Canadians recently adopted a new policy. The Australians have adopted a new policy. Which says your primary obligation is to set high standards for integrity in research. Any departure from that is something we will look into, and there are very serious ones out there.

I have argued for a long time that we need to rewrite our policies in this country so that we get our policy makers and our researchers thinking broadly about their responsibilities and not just narrowly about misconduct.

DR. GUTMANN: So the reason that this is all important, remember, nothing any of you have said right now or anything we have said, is specific to neuroscience, is that that's -- if you will -- the foundation on which all good ethical science is built, and the earlier you can get it established in the life history of science and the institutions that support science, the better.

I think what you said, to set it as the highest standard to which all scientists should aspire, is so much more accurate and inspiring than to think about a set

of minimal standards that you just have to check the box off for.

DR. STENECK: If I could, you would be amazed at how many institutional policies begin with that phrase, including your institutional policy.

DR. GUTMANN: Yes.

DR. STENECK: And yet, they very rapidly then go to the only thing we really need to look at is misconduct.

DR. GUTMANN: Yes. I am strongly and avidly supportive and all the evidence supports beginning that. That doesn't mean you shouldn't have policies for misconduct because some of you, I think, backed off a little that it should be less punitive, more -- I believe we have to be punitive when senior scientists violate, knowingly violate, or they should have known and they violated, and we clearly have the policy in place.

If we didn't have the policy in place, then you can't hang an individual out to dry, and then, we have to get the policy in place.

We have to do both, right, Nick? You have to set high aspirations, but there have to be some repercussions beyond just not publishing your article, if you falsify data.

Ushma, I think you would be the first to agree that not all the examples are students who go off and do it. Sometimes the scientist is so convinced of the rightness of his science that all of the incentives he puts out there are for his students to agree with his results. And if they don't, he basically punishes them by not writing recommendations for them or berating the that they didn't do it well.

And that is just human psychology, which neuroscientists should be the first to recognize, right?

So we have to guard against that as well. It discredits all of, or has the potential to discredit all of the good science that the vast majority of people perform.

Nelson, did you have something? I have one more question from members of the audience, but why don't you go first?

DR. MICHAEL: I was just going to comment on my NIH colleague's question. I just think bad science is indefensible. It's a violation of public trust, and since the majority of funding in most countries is provided by their governments, I think that at the least is a poor training model, it could be distracting for the literature, you could send people off in different directions.

There are second and third order effects. I think it is a cardinal sin,

frankly. I think it is something also where at another end of the spectrum, it is something we can fix by training. We do the training of students. We should be training post-docs and junior faculty that research integrity means integrity of databases, it is important.

You may not mean to be sloppy, but if you are sloppy, it has consequences. I think it's very serious.

DR. GUTMANN: Ushma?

DR. NEILL: You will note I was not particularly shy about revealing author's names especially on the retraction notices that I put on here.

DR. GUTMANN: We admire you for that, actually. There is no reason to hold those people --

DR. NEILL: It was done deliberately, and I know that this will be on the Internet in gratuity, because I felt very strongly about this.

Echoing what Peggy said, there is an enormous number of man-hours that get put into this, and usually, when a journal, especially my journal, issued a retraction, there was an accompanying editorial.

So we were trying to corral about what people could learn from the process or learn from what happened. And in the case, from my personal values, hurting experimental animals, it is a privilege to use animals for research, it is not an automatic right, and when he was reporting on what he did with his animals, it was a very easy decision for the journal, after the correct procedures were put in place, to retract it, and that is also part of why it was put into this presentation, and a lot of other journals -- this is one of the values of a website like Retraction Watch.

I didn't mean to say it was demeaning that they were reporting on every correction or retraction. It's an interesting part of science hype. I'm not sure if Tim Caulfield agrees with that, but pointing a finger at people who were doing things wrong can sometimes mean because of the amount of attention they get, are we all wrong or should we all be hiding? Sometimes it's a little cringe-worthy to look at all of it, but it is also an important function of self-regulation.

DR. GUTMANN: Yes, well put. Ethan Jorgensen-Earp, are you here? From the American Academy of Pediatrics. Much of the description of neuroscience and the ethics surrounding neuroscience research focuses on issues of the developed brain such as Alzheimer's Disease. The NIH describes as the mapping of circuitry, indeed, the NIH describes BRAIN, the BRAIN initiative, as the mapping of circuitry and development.

However, a child's brain is still forming these pathways and developing

new neuronal connections -- I'm having a hard time reading this -- that lead to dramatic developmental changes.

Where do children fit in your deliberations? Will they receive more ethical protection or will this be a future conversation due to the very complex situation of incorporating children in scientific research?

So, let me just preface this, it's not an answer, but we have dealt with one enormously complex and challenging issue that focused exclusively on research with children and testing anthrax vaccines.

We educated ourselves including having an education from amazingly forthcoming representatives of the medical pediatric community on the difference between children and adults, but with regard to the ethics of neuroscience, we haven't yet discussed the implications for children.

And I wonder, Steve, if you want to say something about the difference on the clinical or research side in dealing with children and adults.

Let me just say, everything we have said, we have been directing -- having adults in mind rather than children.

DR. HAUSER: I think this is a very good point and an important point. I might say two things. First, that the BRAIN Initiative and I think the neuroscience agenda absolutely is focused on the important neural developmental problems that affect children.

Second, that I think it is going to be very important for us to consider some of the ethical issues, and there are also a number of practical issues that are limitations to what is feasible in children. For example, fMRI, in very young children, which requires children to sit still.

Beyond that, I don't have much else to say.

DR. GUTMANN: Having focused on children, everything we have discussed applies because if there needs to be consent, and children can't give informed consent, there are different standards and so on, but we haven't really focused on the particular issues of the developmental nature of children's brains. Did someone want to -
- yes, Eric -- address this?

DR. RACINE: Just perhaps want to make a short comment because I'm involved as the co-lead on a neuroethics platform for a National Center of Excellence dedicated to neurodevelopment. It's called NeuroDevNet, and this is a rather large and sizeable research group that spans basic neuroscience up to KT or knowledge transfer and so on.

I've been exposed now for four years to different areas of neurodevelopmental science, and what is very striking in my eyes is when we look at the ethics literature for conditions like cerebral palsy, first leading cause of physical disability in children, or fetal alcohol spectrum disorders, a leading cause, that is preventable, of disability, there is not much ethics discussion around these conditions, whether it is from the clinical or public health standpoint or from the research ethics standpoint, there is a bit of a blind spot, I would say, not necessarily generally speaking, but when we are more sensitive to the unique contexts in which these parents, mothers, children are in, I think there is probably a need somehow for someone to look further into those issues.

It seems like from the bioethics literature standpoint, there are a series of blind spots.

DR. GUTMANN: I'm open for any other questions or comments from presenters or Commission members before wrapping up. Anybody? Jim, why don't I turn it to you to wrap us up.

DR. WAGNER: I am happy to wrap up. I want to thank --

DR. GUTMANN: Dan?

DR. SULMASY: Just one other question, while we have been talking a lot about what journals can do, for instance, and a little bit about educating scientists, I am wondering if there are best practices you all know about, about how to handle some of these problems at a local level.

For instance, is there training for PIs anywhere about how to handle the situation when you find out somebody is not censoring their outliers or splicing the gels under your watch?

Is there training for that? Is this within the scope of research ethics consultation? Are there other ideas about how to address this locally other than sort of reporting people and acting punitively?

DR. MASON: I'm really interested in trying to stop the problems before they occur. We did make Ethics@sfn.org. I publicized that e-mail address intentionally, informing the membership that we're there with the aim to serve and be responsive to the membership's needs.

And to date, we are still on a couple of handfuls, but I've gotten a couple of handfuls of inquiries before things come into submission. So I am pleased with that.

I think there has to be this non-judgmental open availability for consult.

DR. STENECK: There is actually a funded program at Washington

University at St. Louis for training researchers who have been found guilty of misconduct. There is a rehabilitation program that is based on the model we use for doctors who have done things that are unethical.

I think it is important because the other option is to drum them out and you lose all that experience and so on. It's small, it doesn't do very much.

I think the biggest single problem we have is training the trainers. Every time you come to a good course option, as soon as you look at the cost of scaling it up, it's enormous. There is no way we can scale up a really good research ethics course to cover the 20,000 researchers at the University of Michigan that we have to train.

It is that scalability problem that becomes an issue, and I think that is where we are not focusing enough attention.

And I think one of the reasons for that is we haven't prioritized what the problems are. There has been a huge slate of problems put out here today, from what the researchers are doing to what the journalists are. If you really want to save the public's investment in research, where would you focus your attention? We haven't addressed that issue.

We still put a lot of money into misconduct. It probably is necessary but it doesn't do a whole heck of a lot, and we don't put a lot of money into other problems which may be costing us in some cases hundreds of millions of dollars in wasted clinical research grants and things like that.

Until we prioritize, we don't have the resources to train everybody, it is going to be very difficult to come up with solutions.

DR. SULMASY: Where would you prioritize?

DR. GUTMANN: Thank you, Dan, thank you.

DR. STENECK: As I said, when I worked with the research program at ORI, we tried for many years to encourage economists to actually come in and look at these issues.

There has been strikingly little economic analysis of the benefits and risks within research, and most of the economic analyses are done by researchers who want to demonstrate benefits. There has really been no critical cost-benefit analysis of research.

I'm working in the area of biorepositories right now and getting enormous push back that I shouldn't even ask those questions.

It is obviously in the area of clinical research because that is where you

have the greatest impact on the people, where you put the most money in, but even within that, what are the problems, are they the publication problems, are they the bias problems and so on.

If we could figure that out, then I think we could better target our educational efforts as to what we need to do. Right now, we don't have the resources to do what we need to do and we don't know where to target our efforts.

DR. NEILL: If I could make another short comment about freeness of journal editors and the experience of being willing to go out and train people. I wish David Wright was still here because he could maybe speak to what the ORI does, at least here within the United States.

If there was an allegation brought forward to our journal that was something that was beyond the scope of what I could investigate or looked like it was a larger thing and we needed to refer it, there's a research integrity officer embedded in every publicly funded U.S. institution. If there was any sort of a question, I would call up a contact at the ORI and find out who that RIO was, that research integrity officer, and they would take it from there.

Now, one of the reasons why I am here is because I met someone from here who heard me give a talk at the ORI at 20 conference, which was a conference for research integrity officers. So they get continual training.

They are the ones also doing the administration of the RCR courses, or at least that is who is doing the training at Memorial Sloan-Kettering, is the person who is the research integrity officer.

Through that program is how a lot of the dissemination happens. If you think about it in terms of scale, that's a slightly smaller scale, like I don't actually know if that is where you could target some of the resources then.

DR. GUTMANN: Eric?

DR. RACINE: A quick response. I think asking or talking about best practices summons two key questions. What is the goal of the practice or the why question, and the methods question of how. I think there is a wide range of goals that can be pursued.

For example, in my unit, we train grad students who are actually registered in neuroscience but we get them to do Master's and PhD theses in neuroethics.

I think that is probably an interesting way of developing creative ethics thinking and building up deeper resources to get the younger generation to be involved in solutions.

I'm not sure that is necessarily a good strategy to make people more -- I hope it is, but not necessarily -- to make them more compliant or more uniform in terms of practices.

I think those are really different types of goals and different kinds of methods, and we would need probably more data to inform RCR strategies and see what's the value of an ELSI program, RCR, research integrity. These are all different types of goals and involve different kinds of methods or practices. You need kind of an outcome measure that is realistic, that captures outcomes based on who is involved in those programs.

It speaks to the complexity, I think.

DR. STENECK: Just to give you a couple of numbers because the ORI program is a wonderful program. It trains 25 people at a session. I think it does two or three a year. There are 4,000 institutions that are subject to ORI regulations, and I believe the study showed that the RIOs turnover about every two years.

Think about what the level of training is, if you get a good RIO at a journal, you are in great shape. If you get one that came on the job two weeks ago and hasn't gotten any training, you get no help at all.

DR. GUTMANN: Many of us are in institutions which take ethics and science very seriously and invest in it. I have to say while I am all in favor of making sure when we put resources some place, it has some strong rationale behind it, I think we are kidding ourselves if we think that the integration of ethics into all of science can be done without the injection of some additional resources. At the same time, the amount of resources it takes, especially if you follow what we all agree on, so Raju and I agree on this, that it is not as if there is one model. There are multiple models that can be adjusted to what the institution finds most conducive to producing some improvement.

The resources are minimal compared to what the resources are for doing the rest of big science, and doing big science, the resources are small compared to some of the other big spends that our society makes on things that are a lot less generative of social and economic progress.

I think we just have to really figure out the models that have showed some signs of working and be willing to argue for investment in them because it is not a huge investment that we are talking about relative to what the benefits are, which are to assure ourselves and our institutions, which we are doing already.

As importantly, to assure the public that there is real integrity in the science, that is a public -- I don't know who said it -- was it Peggy, we all agree it is public trust, that we want scientists to have the autonomy and academic freedom that they do, because that's the way you can best fulfill the public trust, but you can only do

that if we can also assure the public on reasonable grounds that there is true integrity in the vast majority of science that goes on.

With that, I'm going to turn it over now to my wonderful Vice-Chair, Jim Wagner, to conclude.

DR. WAGNER: That was well worth the extra time. Thanks to our panel. Over the course of the day, we have covered a lot of ground, as you pointed out.

It seems to me a quick summary may be that we have all agreed that the integration of bioethics must be more than a layering on of requirements to be met, some minimal standard, as some burdensome task, but rather adopted as a culture, whereby our researchers would eagerly uphold and even set standards, not just meet them.

Secondly, a lot of good conversation about the enormous potential for ironing out the cycle of hype and developing instead a pipeline of trusted communication.

We spent a lot of time talking about the power of training and education and also the need for prioritization and resources to get all that done.

Thank you all for a terrific day.

(Applause.)

DR. GUTMANN: We will reconvene tomorrow at 9:00.

(Whereupon, at 3:26 p.m., the meeting was recessed, to reconvene the following day, Tuesday, February 11, 2014, at 9:00 a.m.)

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